

**397 Exploring adolescents' adherence to CF treatment regimes**

J. Cowland, S. Carr. *Dept of Paediatric Respiratory Medicine, Barts & the London Children's Hospital, London, UK*

**Introduction:** The aim of this study was to explore adolescent's perceptions of adherence to CF treatment regimes.

**Methods:** A pilot questionnaire was sent to teenagers with CF between the ages of 13 and 18 years. It explored adherence, the levels of dependence on the family and which factors affect adherence. It determined which treatments are "most difficult" and "easiest" to adhere to. Data was collected using qualitative and quantitative methods including open-ended questioning and categorical scales.

**Results:** 20/36 responded (56%), 8 male, mean age 15 yrs. There was a significant improvement ( $p=0.004$ ) in the adherence level reported by participants when well (40%) compared to unwell (90%). 75% cited that the reasons for the improvement in their adherence were health related when they are unwell. 80% miss treatments at least once a week. 30% stated physiotherapy was the most difficult treatment. 50% felt taking tablets was the easiest. No correlation was found between the most difficult treatment and that treatment missed the most. When examining what would make treatment easier, speed was the major factor for 40% and time a recurring factor when considering what was most difficult. All participants reported they were given help by their family to complete treatments, with 50% receiving this most of the time.

**Conclusion:** This study found the level of adherence significantly improved when adolescents were unwell. Responses given demonstrated time is a major factor for many and ease of medication administration is important. This treatment burden was described as the "worst thing" about having CF and should be considered when trying to improve care. This study has given insight into adolescents' perceptions of adherence to CF treatment; highlighting adherence is an issue for the adolescent population with CF.

**398 An annual review tool: assessing nursing and psychological needs**

B. Yorston, C. Mees, J. MacCallam. *Lifetime Service, Community Child Health, Bath, UK*

**Aims:** This project aimed to develop a nursing annual review tool to ensure seamless, holistic care for families, to improve communication within the CF team and to provide a comprehensive, equitable mechanism for continuing reassessment.

**Methods:** The inspiration for this project came from reflection on current practices in multi professional working with CF families. The tool was designed following feedback from families and in consultation with community children's nurses, clinical psychologists and a consultant paediatrician.

The working group identified key areas of information that needed to be collected as part of the annual review assessment. Amongst others, these areas included current respiratory status, equipment needs, school liaison, current needs for information within the family and current coping with the demands of living with CF. Topic questions were developed for each of the key areas to aid the nurse using the tool and to ensure comparable assessments. The working group devised a workable and clear form where information could be succinctly recorded and easily disseminated to the multi-professional team. Throughout this process the working group consulted the wider team. A six-month pilot was commenced whereby the review tool began to be used for each annual review assessment. Nurses complete an audit form for each annual review which is then used to evaluate the tool's effectiveness.

**Results:** Early audit information suggests that this tool is producing positive benefits on practice, with the project aims being met. For example, communication between members of the CF team was improved.

**Conclusions:** At the end of the pilot stage this tool will be modified according to the outcome of the audit and any other feedback from families and professionals. The anticipated conclusion is that this tool will become part of our ongoing practice, reviewed on an annual basis.

**399 A descriptive survey designed to assess parents satisfaction with the Cystic Fibrosis annual review process at the Sheffield Children's NHS Trust**

S. Bott<sup>1</sup>, A. Lacey<sup>2</sup>, T. Elliott<sup>1</sup>, N. West<sup>1</sup>. <sup>1</sup>Sheffield Children's NHS Trust, Sheffield; <sup>2</sup>University of Sheffield, Sheffield, UK

Annual Review visits are an integral part of effective disease management for patients with cystic fibrosis (CF). The objective of this descriptive survey was to explore parents' perceptions of their child's annual review and to generate an overall rating of satisfaction. The eligible population consisted of 159 patients from a single CF centre. The unit sees two categories of patient: those who attend Sheffield Children's Hospital (SCH) only ( $n=97$ ) and those whose care is shared between SCH as the Regional Centre and a local District General Hospital (DGH) ( $n=62$ ). A confidential questionnaire was posted out in May 2005 to 123 sets of parents eligible to participate in the study. Seventy-six questionnaires were returned giving an overall response rate of 62%. How the annual review is conducted in terms of organisation of the day, the decision-making process regarding clinical management changes and how results are fed back was measured using a 5-point Likert Scale. Overall, 89.5% of parents were satisfied with the annual review. Sheffield parents have the highest level of satisfaction (94.5%) compared to DGH parents (76.2%). One open-ended question asking for respondents' qualitative comments on the care received and possible areas for improvement was included. When analysed, qualitative comments provided insight into positive aspects of the existing service as well as recommendations for future improvements.

**400\* Effecting change with creative thinking: outpatient intravenous antibiotic utilisation**

R. Player. *Adult CF Service, Royal Adelaide Hospital, Adelaide, Australia*

**Introduction:** Patients with Cystic Fibrosis (CF) are now living longer. For many adults, life has become more complicated balancing management of their chronic condition, employment, education, relationships, marriage and parenthood. Hospital admissions add further complications. The existing model of intravenous antibiotic delivery did not effectively cater for adult needs, either as an inpatient, or when the treatment at home was preferable. This led the Adult Service to develop a range of care options that were client focused.

**Methods:** Action research was the primary methodology. A range of surveys and questionnaires were conducted with clients, key stakeholders and staff. A database was established to identify referral patterns, service utilization, client and resource requirements, client and staff satisfaction and outcomes.

**Summary:** This work resulted in the development of the Outpatient Intravenous Service (OPIVS). This included a pathway of management, eligibility and referral criteria, appointment planner, consent process, education package for clients and carers, management guidelines manual, policies, procedures and protocols.

**Conclusion:** Two thirds of adult patients with CF, requiring intravenous treatment, were eligible for the OPIVS. Two thirds of patients, eligible to continue treatment with the OPIVS, continued treatment at home after discharge from hospital. Three quarters of eligible patients assumed responsibility for their own care. Uptake and completion rates improved with training, education and support to patients and carers. The majority of adults, eligible to commence or continue treatment in the OPIVS, were assessed to be capable of successfully completing treatment outside the hospital environment.